

# Initiating pain and palliative care outpatient services for the suburban underserved in Montgomery County, Maryland: Lessons learned at the NIH Clinical Center and MobileMed

SUNIL K. AGGARWAL, M.D., PH.D.,<sup>1</sup> AMRITA GHOSH, M.D., PH.D.,<sup>1</sup>  
M. JENNIFER CHENG, M.D.,<sup>1</sup> KATHLEEN LUTON, R.N., M.S.N., C.R.N.P., COHN-S,<sup>2</sup>  
PETER F. LOWET, M.B.A.,<sup>2</sup> AND ANN BERGER, M.S.N., M.D.<sup>1</sup>

<sup>1</sup>Pain and Palliative Care Service, Clinical Center, National Institutes of Health, Bethesda, Maryland

<sup>2</sup>Mobile Medical Care Inc., Bethesda, Maryland

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## ABSTRACT

*Objective:* With the ongoing expansion of palliative care services throughout the United States, meeting the needs of socioeconomically marginalized populations, as in all domains of healthcare, continues to be a challenge. Our specific aim here was to help meet some of these needs through expanding delivery of pain and palliative care services by establishing a new clinic for underserved patients and collecting descriptive data about its operation.

*Method:* In November of 2014, the National Institutes of Health Clinical Center's Pain and Palliative Care Service (PPCS) launched a bimonthly offsite pain and palliative care outpatient clinic in collaboration with Mobile Medical Care Inc. (MobileMed), a private not-for-profit primary care provider in Montgomery County, Maryland, serving underserved area residents since 1968. Staffed by NIH hospice and palliative medicine clinical fellows and faculty, the clinic provides specialty pain and palliative care consultation services to patients referred by their primary care healthcare providers. A patient log was maintained, charts reviewed, and referring providers surveyed on their satisfaction with the service.

*Results:* The clinic had 27 patient encounters with 10 patients (6 males, 4 females, aged 23–67) during its first 7 months of operation. The reason for referral for all but one patient was chronic pain of multiple etiologies. Patients had numerous psychosocial stressors and comorbidities. All primary care providers who returned surveys ( $n = 4$ ) rated their level of satisfaction with the consultation service as “very satisfied” or “extremely satisfied.”

*Significance of Results:* This brief descriptive report outlines the steps taken and logistical issues addressed to launch and continue the clinic, the characteristics of patients treated, and the results of quality-improvement projects. Lessons learned are highlighted and future directions suggested for the clinic and others that may come along like it.

**KEYWORDS:** Palliative care, Pain management, Underserved, Maryland, Suburbanization of poverty

## INTRODUCTION

Palliative care and pain relief are increasingly recognized as cost-effective and quality-of-life promoting universal human rights for those with serious or advanced illness (WHO, 2014). In the United States, palliative care services for hospitalized and hospice patients have begun to expand their scope of service

Address correspondence and reprint request to: Sunil K. Aggarwal, National Institutes of Health, Clinical Center, Pain and Palliative Care Service, 10 Center Drive, 2-1733 MSC 1517, Bethesda, Maryland 20892. E-mail: [sunila@uw.edu](mailto:sunila@uw.edu).

upstream to reach ambulatory patients in outpatient clinical settings as well as in home-based programs (Beresford & Meier, 2008). However, like with many areas of healthcare, tremendous socioeconomic disparities exist that limit patient access to palliative care specialty services (Kayser et al., 2014).

One way to help bridge this gap is for established palliative care services at medical centers to partner with healthcare organizations that have already made inroads in providing ambulatory healthcare services for underserved populations. For example, palliative care subspecialists at regional medical centers can partner with community-based primary care health systems and serve as internally referred palliative care consultants to primary care providers. Palliative care consultants can then site outpatient clinics in the same locales where such patients receive primary care so as to remain equally geographically accessible to such patient populations. The present report describes the experience of the National Institutes of Health Clinical Center (NIH-CC) Pain and Palliative Care Service (PPCS) with one such partnership leading to initiation of an outpatient pain and palliative care clinic in Rockville, Montgomery County, Maryland, which started in November of 2014 and remains ongoing. While there is a plethora of hospices and inpatient palliative care services in hospitals in the county, there are virtually no outpatient palliative care clinics. This article is intended to summarize our experience with expansion of pain and palliative care health services for underserved populations just beyond our institution's walls and presents some of the basic lessons learned. It addresses the geographic setting, logistics, operation, initial clinical experiences, quality improvement projects, and future directions of the recently launched clinic.

### Geographic Setting

Montgomery County, Maryland, population approximately 1 million, is a suburban county to the north of Washington, D.C. It has consistently ranked as one of the wealthiest counties in the nation (in 2010, it ranked 12th in annual household median income: \$98,221) (Kneebone & Berube, 2013; U.S. Census Bureau, 2015). And yet, despite this rather impressive wealth, countywide socioeconomic disparity has been increasing. In recent years, the county has undergone significant demographic transformation, and increasing-sized pockets of poverty have arisen, concordant with a national trend known as the "suburbanization of poverty." There was a loss of more than 37,000 jobs in the county between 2007 and 2010, with a 66% rise in residents living below the poverty line over that same period (Kneebone

& Berube, 2013). In 2014, the countywide poverty rate was 6.5%; however, this figure is based on the federal poverty line, which, according to some scholarly estimates, may underestimate an annual living wage for a family of four in the county (\$49,979) by more than a factor of two (Turque, 2014). In terms of ethnic composition, in 1990 immigrants accounted for fewer than one in five residents; in 2010, immigrants accounted for nearly a third of the population and nearly 40% of residents in poverty (Kneebone & Berube, 2013). Not surprisingly, given these socioeconomic conditions, healthcare access challenges persist in Montgomery County. In 2012, 10% of adults in the county surveyed by telephone reported that there was a time in the prior 12 months when they were unable to afford to see a doctor (Healthy Montgomery, 2014a). While tens of thousands of residents have enrolled for health insurance since implementation of the recent federal healthcare and insurance reform legislation, 12.8% of county residents remain uninsured (Healthy Montgomery, 2014b). State officials have projected that approximately 60,000 Montgomery County residents will remain uninsured after implementation of the federal healthcare reform (MobileMed, 2015).

### MobileMed

Founded in 1968, MobileMed's mission is to improve the health of low-income people who face the greatest barriers to care access. MobileMed is a private non-profit safety-net primary care provider that serves uninsured adult patients whose incomes are below 250% of the federal poverty guideline by providing multicultural primary and preventive care. Homeless patients receive free care, and, with the healthcare reform, MobileMed has also begun providing primary care to patients who are now eligible for Medicare and managed Medicaid insurance plans. MobileMed operates fixed-site and mobile medical van clinics at nine public-transit-accessible locations across the county. In 2014, they provided healthcare to 5,000 low-income county residents, with a total of 14,000 clinical encounters. These patients hailed from more than 100 countries and spoke 25 languages. In terms of staffing, MobileMed is staffed by 5 full-time paid midlevel healthcare providers and clinic coordinators and more than 50 volunteer clinicians who work anywhere between 2 half-days a month to 1–5 days a week. In addition to services in English and Spanish, several of the primary care clinics have scheduled sessions each week that cater to other specific cultures/languages (e.g., French, Korean, Farsi, and Amharic). Beyond primary care, patients have access to specialty care, either through internal providers or two volunteer specialty care

networks, in the areas of ophthalmology, neurology, rheumatology, pulmonology, gynecology, cardiology, endocrinology, nephrology, gastroenterology, orthopedics, podiatry, optometry, psychiatry, and behavioral health. MobileMed patients also have access to pro-bono diagnostic testing through partner hospitals and related organizations.

## METHODS

### Clinic Initiation and Operational Logistics

Located in Bethesda, Maryland, in southern Montgomery County, the National Institutes of Health Clinical Center, with 242 inpatient beds and 90 day-hospital stations, is the largest research hospital dedicated to translational clinical research. Its pain and palliative care service (PPCS) was established in 2000 and serves as a consultative service to provide comprehensive and effective palliation of symptoms and treatment of physical, psychological, emotional, and spiritual suffering for individuals enrolled in clinical research protocols with advanced conditions that limit or threaten life, including support for their families. The PPCS also holds a twice-weekly onsite outpatient clinic. The impetus to establish an additional NIH–CC palliative care outpatient clinic offsite in conjunction with MobileMed (MM) came about through an invitation in 2014 to start such a clinic from an MM volunteer physician who contacted the director of the NIH–CC pain and palliative care service.

From the standpoint of graduate medical education and training, the clinic provides a rich training experience for fellows and other trainees who rotate through the NIH–CC PPCS. Establishing a palliative care clinic at MM led by fellows not only has helped to teach the basics of how to go about setting up a clinical service in an institution, but it also allowed a way to help fulfill hospice and palliative medicine clinical fellows quality-improvement project completion mandates as per the training guidelines of the Accreditation Council of Graduate Medical Education. Additionally, while the PPCS already provides care to inpatients and outpatients enrolled in clinical research protocols at the CC who do at times come from geographically underserved areas or population segments in the United States or internationally, it was felt that providing pain and palliative care services to local underserved patients would be a way to help reduce social health disparities and give back to communities in Montgomery County, where the NIH–CC is located. Two departments at the NIH–CC, endocrinology and cardiology/cardiothoracic surgery, had already launched

community clinics in partnership with MM, which helped to establish a precedent for a pain and palliative care clinic.

The launch of the clinic was carried out in three stages. With the assistance of an informationist, the first stage involved a review of the published medical literature on the establishment of outpatient palliative care clinics at medical centers in order to develop a general set of referral criteria or “palliative care consult triggers” and exemplar palliative-care-appropriate patient vignettes for MM primary care providers. Tailoring these criteria to the needs of the MM primary care clinical team required meeting and dialoguing with MM staff leadership several months in advance to better understand the health characteristics of their patient population, such as prevalent illness types and severity, and to gauge their level of comfort with and understanding of pain and palliative care. It was discovered that the age range of the majority of patients seen in MM primary care clinics was 45–64 years old. Moreover, while MM clinical leadership identified a high prevalence in their patient panels of conditions such as coronary artery disease, diabetes, congestive heart failure, arrhythmias, deep venous thromboses, and chronic wounds, as well as such prevalent psychosocial issues as undocumented immigrant status and a history of torture, they did not identify at the outset any patients who had terminal diagnoses or were nearing the end of life. Thus, palliative care referral criteria (or consult triggers) shared with MM staff de-emphasized cancer and terminal diagnoses and emphasized a wide range of chronic or progressive illnesses, difficult to manage non-pain symptoms, and especially emphasized was referral of patients with chronic nonmalignant pain who were not well diagnosed or managed.

The second stage of the clinic launch required creation of a memorandum of understanding between the two systems, which included the necessity for the pain and palliative care clinic to remain in a strictly consultative role—meaning, for example, that the clinic would be recommending rather than directly ordering patient medications. The third and final stage of the launch included creation of an electronic medical record charting plan and finalization of the clinic’s location, schedule, and staffing. Recognizing the need to start slowly, the NIH/MobileMed PPCS Clinic was scheduled bimonthly for the first two Wednesday afternoons of each month, from 1:00 to 5:00 p.m. New patients would be allotted one-hour appointments, and follow-up patients 30 minutes. The clinic would be staffed by hospice and palliative medicine clinical fellows, who mainly alternated, and one attending. A retired registered nurse who previously worked in a pain management private practice also

chose to observe and occasionally helped with history taking and patient instructions.

To allow for service tracking, trend discernment, and aggregate analysis of patient care activities, a clinic patient log was created and maintained. The log was kept electronically on a restricted-share drive and tracked the following fields for each patient encounter: date seen; whether new or follow-up visit; medical record number; age; sex; ethnicity; reason for consult; insurance status; referring provider; primary diagnoses; cancer?; pain/palliative working diagnoses; addiction history?; hospice candidate?; intervention; other notes. A tally was kept for referred patients who missed appointments. Other data, such as psychosocial stressors, were gleaned from chart review.

## RESULTS

### Characteristics of Patients Treated

From November 5, 2014, to May 13, 2015, the clinic had 27 patient encounters with 10 patients (6 males, 4 females, aged 23–67). The ethnic backgrounds included Ethiopian, Syrian Armenian, Iranian, Caucasian, African American, and Salvadoran American. With the exception of one patient who was referred for insomnia and labile affect after a stroke, all patients seen were referred for chronic pain. The working etiologic pain diagnoses included complex regional pain syndrome, osteoarthritis, diabetic peripheral neuropathy, peripheral vascular disease, multiple-sclerosis-related central pain, chronic lumbar radiculopathy, myofascial pain, and other musculoskeletal and soft-tissue disorders. Patients had such comorbidities as diabetes, hypertension, cardiovascular disease, stroke, multiple sclerosis, Ollier's disease (a sporadic disorder of asymmetric skeletal endochondromas), prior motor vehicle accidents, prior gunshot wounds, posttraumatic stress disorder, depression, anxiety, and bipolar disorder. Psychoso-

cial stressor histories included domestic abuse, sexual assault, violent death of a primary caregiver in childhood, loss of a child, pending deportation, homelessness, unstable housing, and loss of employer-based health insurance (Table 1).

Management included a range of activities, such as supportive listening and counseling, internal specialty referrals, radiological testing recommendations, opioid and nonopioid medication recommendations, and nonpharmacological recommendations for symptom management. All patients except two lacked health insurance. A special exemption was requested from MM staff to allow one patient who had obtained it during the course of his treatment and to continue to be seen by the clinic, as insured patients at MM typically are not eligible to be seen by internal voluntary specialty care providers. Another insured patient had Medicaid but was homeless and therefore allowed to see all specialists. The average no-show rate for the clinic was 42%, a rate not uncommon for other MM clinics. There were no hospice-appropriate patients, and there were two patients with addiction histories or concerns.

### Quality Improvement Projects: Education and Feedback Solicitation

An important aspect of the clinic launch was recognizing the need for education of MM clinicians and staff in palliative care and in the role and function of the palliative care consultant clinic. Basic lectures on palliative care were given as an in-service educational program, one to MM staff clinicians and support staff and one to volunteer clinicians, by NIH hospice and palliative medicine clinical fellows. Included in these lectures was: education regarding why healthcare providers should be familiar with palliative care; basic palliative care skill sets including pain and other symptom management; psychosocial, emotional, and spiritual evaluations; how to lead basic conversations regarding advanced care planning; and how to know when patients would

**Table 1.** NIH/MobileMed Pain and Palliative Care Clinic patient characteristics

Gender	6 males, 4 females
Age	23–67
Ethnicity	Ethiopian, Syrian Armenian, Iranian, Caucasian, African American, Salvadoran American
Working pain diagnoses	Complex regional pain syndrome, osteoarthritis, diabetic peripheral neuropathy, peripheral vascular disease, multiple-sclerosis-related central pain, chronic lumbar radiculopathy, myofascial pain, and other musculoskeletal and soft tissue disorders
Comorbidities	Diabetes, hypertension, cardiovascular disease, stroke with pseudobulbar affect, multiple sclerosis, Ollier's disease, prior motor vehicle accident, prior gunshot wounds, posttraumatic stress disorder, depression, anxiety, bipolar disorder, addictive disorders
Psychosocial stressors	Domestic abuse, sexual assault, violent death of a primary caregiver in childhood, loss of a child, pending deportation case, homelessness, unstable housing, loss of employer-based health insurance

benefit from referral to specialty palliative care and to hospice. When queried for demographics and practice characteristics, individuals who underwent the educational program reported that they ranged in age from 23 to 58; practiced in private practice, community clinics, and MM; had practiced clinically from 6 months to 20 years; and generally had 0 to 5 patients in total who were prescribed opioids.

Over time, it was seen that the number of primary care providers referring patients to the clinic increased. In the first half of the seven-month operational period of the clinic after launch, new and follow-up patients were seen from only two referring providers. In the latter half, patients from three additional referring primary care providers, for a total of five, were seen in the clinic.

To assess provider satisfaction with palliative care clinic consultations, a brief survey based on previously published work was given to referring providers whose patients had been seen in the clinic (see Schwarz et al., 2012; Selvaggi et al., 2014). Providers were surveyed in person at the two educational sessions held by the palliative care fellows. Two others not in attendance were reached by email. All five primary care providers who had referred patients seen in the clinic through May 6 were reached, and all but one returned survey responses. One nonresponder stated that he had not seen the patient he had referred again. On a 5-point scale, with 1 corresponding to “not at all” and 5 to “extremely satisfied,” all four providers rated their level of satisfaction as 4 ( $n = 2$ ) or 5 ( $n = 2$ ). When queried about how much of an impact they felt the pain and palliative care clinic had on the care their patients received, using a 4-point scale (where 1 stood for “no impact,” 2 for “minimal impact,” 3 “moderate impact,” and 4 “significant impact”), half rated the clinic as having a “moderate” impact and half rated it as having a “significant” impact. Three optional additional free response feedback/comments were also given, highlighting the collegial benefit, gratitude, and hope for future build-out.

## DISCUSSION

### Lessons Learned

The initiation of a community-based pain and palliative care clinic in a system that serves exclusively underserved patients who are in poverty or near-poverty has presented several important lessons that may be useful to consider for those who wish to similarly expand pain and palliative care services. The following, in no particular order, are some of the lessons gleaned thus far:

1. Given the high prevalence of chronic pain, palliative care services have to be presented to the underserved health services community provider as absolutely encompassing the provision of care to patients with chronic and persistent pain of all etiologies, not just supportive care of those with life-threatening illnesses.
2. It is important to work to offer primary pain and palliative care education to help expand the skill set of primary care providers and to help them recognize appropriate patients for referral. This educational outreach, which could occur through inpatient services or by joining inpatient care rounds during operation of primary care or other specialty clinics, should endeavor to reach nonclinical support staff as well, to help provide institution-wide education.
3. It is especially important to reach out to paid staff providers before volunteer providers for education and referral base building, as staff providers tend to have a higher caseload and tend to be seeing patients more consistently.
4. Given the extra layer of coverage and after-hours medical supervision needed for issuance of prescriptions, it is important that a bimonthly pain and palliative care clinic maintain a consultative role rather than a direct care provider role, with all the standard etiquette and referring provider communication protocols that this entails. However, in a consultative role, the clinic can feasibly directly refer patients to other services, as appropriate.
5. For an underserved patient population with a high prevalence of ethnic minorities, poverty, and legal barriers such as undocumented immigration, it is important that the comprehensive psychosocial-spiritual diagnostic evaluation that is part of palliative care probe for patient distress related to socioeconomic and sociolegal obstacles, with supportive care provided as appropriate.

### Future Directions

To continue to get the word out about the clinic, in addition to a recently placed article in the MM newsletter announcing the clinic launch, creation of a patient-centered brochure about the clinic's services is planned. It was recognized that patients could benefit from spiritual care services and complementary and integrative medicine modalities, the latter often being unaffordable or inaccessible to low-income and uninsured patients. An integrative medicine approach that blends complementary approaches with

traditional medical practice is becoming a standard approach in the field of palliative care medicine and chronic pain management, and such approaches have been integrated into the inpatient and outpatient activities of the NIH–CC PPCS since its inception. One acupuncturist and Tui Na practitioner in the community who is known to NIH PPCS staff has agreed to volunteer her time to treat select patients six hours a month. Additional acupuncturists, as well as massage therapists, including those in training, are being sought to build up a volunteer pool. Spiritual care volunteers, especially those with bilingual or multilingual language proficiencies, are additionally being sought.

Additional attending staff clinicians in the NIH–CC PPCS plan to begin volunteering in the clinic. Other clinical fellows in hospice and palliative medicine or pain medicine from area programs who rotate through the NIH–CC for training could begin to work and learn at the clinic, as one fellow was already able to do. Finally, patients at the clinic at MM could potentially begin to be recruited to participate in natural history protocols or other clinical research studies being conducted at the NIH–CC, thereby allowing patients an opportunity to access the PPCS and other services and participate in investigations at the world's largest research hospital.

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